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CUTTING THE TIES: STERILISATION OF PERSONS WITH DISABILITIES NEW PERSPECTIVES AFTER THE INTRODUCTION OF THE CRPD

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1. Introduction

In August 2013 a British Court of Protection ordered the sterilisation of a 36-year old man with significant learning difficulties.[1] The man, referred to as DE, was reported to have the mental age of a person between the ages of six and nine and was for that reason legally incapacitated. He was not free to consent to sterilisation. DE was in a long-term relationship with a woman known as PQ who also had learning disabilities of a less severe nature. Following the birth of their child in 2010, measures were taken to prevent another pregnancy including keeping the couple apart and supervising them at all times. This loss of independence led to a serious amount of distress, nearly causing the relationship to break. Both DE and PQ were considered unreliable in using contraceptives and DE had made it clear that he did not want to have any more children. The Court of Protection found the sterilisation to be in the best interest of DE, especially since it was clear that less intrusive contraceptive methods would not be suitable for this couple. This ruling was reported to be ground-breaking and far-reaching because no British court had ever before ordered the sterilisation. In the popular press this order was reported as an example of forced sterilisation.[2] However, the core issue in this case was not non-consensual sterilisation because DE had expressed a wish to be sterilised. It was rather a problem of lack of legal capacity which caused the individual to lose all possibilities to decide on his own sterilisation without a Court considering the matter. The example proves that sterilisation of persons with disabilities in fact poses two distinct problems. Beside the loss of capacity, there is also the more traditional problem of people with disabilities who are forced into sterilisation against their will, without consent or under pretence. These two problems will be discussed in this paper.

In section 3 we will discuss the vulnerability of individuals with disabilities and the protection against sterilisation offered by the ECHR and by the CRPD. We will address non-consensual sterilisation of individuals with disabilities and we will also discuss the protection for individuals with intellectual disabilities. Lastly we will expand on the right for a person with (intellectual) disabilities not to retain

[1] Court of Protection, *NHS Trust v DE,* [2013] EWHC 2562.

[2] "Man with learning difficulties to be sterilised in unprecedented court ruling", *the Telegraph* 16 August 2013, www.telegraph.co.uk; "A truly exceptional case: Court to decide on sterilisation of man with learning difficulties", *The independent* 2 August 2013, www.independent.co.uk; "Court sanctions sterilisation of man with learning difficulties", *The Guardian* 16 August 2013, www.theguardian.com.

his fertility. The case-law of the European Court of Human Rights (ECtHR) will be studied and compared to and contrasted with the newer and more specific CRPD in order to identify common grounds and divergences. We will establish that the European Convention on Human Rights (ECHR), often criticised for being outdated and too vague, is reinterpreted by the Court in an attempt to reflect the protection offered by the CRPD. It will become clear that the transformation is not complete even though the influence of the CRPD is clear.

Before zooming in on sterilisation of persons with disabilities, we will discuss the novelties related to this topic as introduced by the Convention on the Rights of Persons with Disabilities (CRPD). Section 2 contains an introduction to the relevant provisions. This section also deals with the CRPD's new decision-making rules concerning individuals with mental, intellectual or psychosocial disabilities.

2. CRPD: a new legal framework

A. General

In 2006 a disability-specific human rights treaty was adopted by the General Assembly of the UN.[3] A specific instrument was considered necessary because individuals with disabilities had remained largely invisible under previous, universal human rights instruments. A specific instrument offered the advantage of raising the awareness of disability as well as rendering the human rights more specific and thus more readily applicable to disability. It was the first time a Convention was drafted with the active participation of the target group, in this case organisations representing individuals with disabilities. It covers a wide range of rights and should promote equality in many aspects of life.[4]

The CRPD marks a paradigm shift in attitudes towards persons with disabilities. Paternalism, charity, segregation and medical labels need to be abandoned and replaced by the concepts surrounding the newly introduced social model of disability. Contrary to the medical model of disability, the hallmark of a social approach to disability emphasizes social prejudice and stereotypes, rather than individual defects. Persons with disabilities are considered to be another variation of humankind and are therefore equal to others. They are entitled to the same human rights as persons without disabilities. Discrimination against individuals with disabilities is considered the direct result of society's incapacity to accommodate the diversity within itself. Under the social model society no longer needs protection against these individuals. Instead it is recognised that the built environment and society's negative attitude towards persons with impairments are the main factors disabling and excluding these persons. Society needs to be adapted in order to remove these excluding barriers

[3] United Nations Convention on the Rights of Persons with Disabilities (CRPD).
[4] The diversity is great. The CRPD contains provisions on: health, education, mobility, culture, politics, work, independent living, accessibility of information, privacy, freedom of expression etc.

and to promote equality and increase participation and inclusion. The barriers can be of a physical nature such as thresholds, stairs etc. The barriers can also be of an immaterial nature: workplace rules, structures. In the case of intellectually disabled individuals the barriers are usually of a legal nature. Individuals with intellectual disabilities are often considered to lack competence which results in the restriction of their legal capacity and in the appointment of a legal guardian. In practice this means that the legal guardian, and thus not the individual with a disability, exercises control over the person and his affairs.

The difference between the two models of disability becomes blatantly clear when we turn to the US Supreme Court decision *Buck v. Bell*[5] which clearly represents the old model of disability. Justice Holmes, writing for the majority in a case concerning the forced sterilisation of a mentally disabled young woman, remarked that society's welfare would be promoted by Carrie Buck's sterilisation because she would no longer be able to spread her genes. The fact that society was considered to be in need of protection against the genes of a defective young woman clearly indicates the acceptance of the old model. We will establish that this older model and the involuntary sterilisation of Carrie Buck would evidently no longer be possible under the ECHR as well as under the new Convention. Forced sterilisation would be considered prejudicial to her dignity and would contravene the CRPD. This Convention, based on the social model of disability, instead imposes the obligation to make efforts to include Carrie Buck in society and allow her to reach her own decisions, if necessary with support. This support would need to help her keep her sexuality if that was her wish. The protection offered by the CRPD will be discussed below.

B. Legal capacity

The distinction between a voluntary and a compulsory sterilisation depends on the consent given by the person concerned. Consent is a fragile concept when it is used in relation to individuals with intellectual disabilities because these persons are often considered to lack the legal capacity to freely and voluntarily consent. It is often contended that they can never consent to important decisions such as intrusive surgery. In the next part we will uncover the new developments resulting from the introduction of this new instrument and we will explore the views of the ECtHR in order to investigate the extent to which the principles of the CRPD are accepted.

It is commonly accepted that individuals with disabilities, more specifically mental, intellectual or psychosocial disabilities can never be rational, independent and freely choosing people, which leads to the conclusion that they are incompetent to make legally binding decisions. This finding of

[5] US Supreme Court, *Buck v. Bell*, 1927, 274 US 200.

incompetence often leads to a restriction or even a complete deprivation of their legal capacity. Persons with disabilities complained that this restriction was often based on erroneous grounds. In a large number of legal systems a person is considered either capable or incapable and the possibilities for an incapable person to move back into the group of the capable individuals are scarce. In most countries, individuals who are considered incapable before the law are represented or substituted by legal guardians, sometimes the parents or care-givers. Sometimes legal guardians are state employees or other agencies or persons appointed by a court, who in some cases have never met the person. Often decisions are made by legal guardians with or without consulting the individual concerned, while in other cases legal guardians need a Court's approval.[6] The provision of a legal guardian can lead to the situation in which decisions are made without a person's knowledge or input.

The CRPD expressly rejects this scheme of incapacity and legal representation by guardians. The restriction of a person's legal capacity is made increasingly difficult. Under this Convention, the capacities of a person with disabilities are no longer considered static and it is accepted that individuals can learn and grow. Decision making is seen as a variable human attribute and a process of communication. The paradigm shift leads to a new presumption: the vast majority of persons whether or not they have a disability are more or less able to reason and understand the content and consequences of a course of action depending on how much information they receive, in what form the information is received, in what context the information is received, how much time is provided to process the information, and how much time and opportunity there is to discuss or test the information with trusted persons. Acceptance of these premises inevitably leads to the abandonment of complete legal incapacity and the paternalistic concept of surrogate decision-making. Instead it is recognised that some persons with disabilities (as well as some without disabilities) require assistance to exercise their legal capacity.

Article 12 of the CRPD, a true example of the paradigm shift,[7] should help individuals with disabilities to create more self-empowerment and enjoy their inherent rights. The provision guarantees equal recognition before the law and the right to legal capacity in all aspects of life.[8] Capacity is to be

[6] E.S. SCOTT, "Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy", 1986, 35 *Duke Law Journal* (806) 818-821.

[7] N. DEVI, J. BIRKENBACH and G. STUCKI, "Moving towards Substituted or Supported Decision-making? Article 12 of the Convention on the Rights of Persons with Disabilities", 2011, 5 *ALTER, European Journal of Disability Research* 249-264; P. FENNELL and U. KHALIQ, "Conflicting or Complementary Obligations. The UN Disability Rights Convention, the European Convention on Human Rights and English Law", 2011, 6 *European Human Rights Law Review* (662) 667-670; P. WELLER "The Convention on the Rights of Persons with Disabilities and the Social Model of Health: New Perspectives", 2011 *Journal of Mental Health Law* 74–83.

[8] See: N. DEVI, J. BIRKENBACH and G. STUCKI, "Moving towards Substituted or Supported Decision-making? Article 12 of the Convention on the Rights of Persons with Disabilities", 2011, 5 *ALTER, European Journal of Disability Research* 249-264.

understood as the capacity to create, modify or extinguish legal relationships.[9] Paragraph 2 declares that "*persons with disabilities enjoy legal capacity on an equal basis with other in all aspects of life*." Paragraph 3 adds positive obligations. States agree to "*take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity*." States must do what they can to organise support for these individuals and introduce safeguards against abuse of such support. This new decision-making scheme is important as it can be used as a stand-alone obligation but it can also be coupled with all other CRPD provisions. The CRPD Committee has for example referred to legal capacity in emphasising the increased risk of being forced into sterilisation for people whose legal capacity is not recognised.[10]

The nature and extent of the support can vary from person to person and depending on the nature of the decision. Support can be needed on one occasion or always, it can take the form of one trusted person or a network of people. The principle of reasonable accommodations and especially the limit of the disproportionate burden may work to limit the level of support that could reasonably be expected to be provided to persons with disabilities. [11] Only when people are unable to achieve capacity under the scheme of supported decision making, can substituted decision making arrangements be made. These arrangements cannot have a uniform character as they need to be closely tailored to the needs of the individual. [12] Blanket restrictions or deprivations are no longer acceptable. The process articulated by article 12(4) balances the need to intervene with a range of safeguards that are guided by respect for the rights, will and preferences of the person, are proportionate to the degree to which such measures affect the person's rights and interests and are sensitive to the deeply embedded discriminatory attitudes which can colour determination for capacity. This supported decision-making model has the potential to radically change the legal position of individuals with disabilities, but also of elderly people. [13]

Although article 12 was adopted unanimously, it still remains controversial. Practice concerning legal capacity of individuals with disabilities varied greatly between the states. Even after ratification there have been disagreements over the recognition of legal capacity, recognition of supported decision-making models and whether article 12 still offered the possibility of adopting substitute decision-making models such as guardianship. During the ratification process, some countries made declarations and reservations on this article. Canada for example, declared its understanding of the

[9] Background Conference Document Prepared by the Office of the United Nations High Commissioner for Human Rights on the Concept of Legal capacity, Sixth Session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, www.un.org, §24.
[10] CRPD Committeee, Concluding Observations on Spain, 2011, UN DOC CRPD/C/ESP/CO/1.
[11] Article 5 CRPD, on the reasonable accommodation duty is also a strong provision which can be read alone or coupled with other provisions of the CRPD, including article 12.
[12] Article 12(4) CRPD.
[13] On this topic: A.S. KANTER, "The United Nations Convention on the Rights of Persons with Disabilities and its Implications for the Rights of Elderly People under International Law", 2009, 25 *Georgia State University Law Review* 527-573.

provision permits both supported and substituted decision-making arrangements in appropriate circumstances and in accordance with the law.[14] In the drafting process, views were expressed that legal capacity could not be extended to all persons with disabilities. It was pointed out that there could exist a number of individuals with disabilities who would not be able to function even with support and who would therefore need others to make decisions on their behalf. The counterargument was that supported decision making was still preferable because it more fully recognises the right of people with disabilities to equal treatment. Even a high level of support would be more in accordance with this principle than declaring an individual incapable. Although the principles seem relatively clear, it remains to be seen how this provision will be construed by the Committee as well as by the states.

The controversy caused by article 12 CRPD is also perceivable in the case-law of the ECtHR. A decision of 2008 seems to be more in line with the general principles of preserving a person's legal capacity and providing a system of supported decision-making than a decision of 2012. In the 2008 case of *Shtukaturov v. Russia*[15], the ECtHR recognised that the will of a person placed under guardianship had to be taken into consideration when a restriction on fundamental rights, such as the right to liberty, is concerned. The formal restriction of a person's legal capacity cannot lead to complete incompetence. Shtukaturov was a mentally disabled man who had been declared legally incapable upon a request filed by his mother. Unaware of any legal proceedings, Shukaturov missed the hearing and was declared incapable with his mother appointed as his guardian. Attempts to appeal these decisions were unsuccessful. On his guardian's request, Shukaturov was then placed in a psychiatric hospital where various of his rights were limited, such as receiving visits from his lawyer. During the ECtHR proceedings the hospital prevented Shukaturov from communicating with his lawyer. The Court found violations of the Convention because no legal safeguards were offered. Besides the procedural issues, the Court also noted that Russian legislation envisaged only one measure of protection for adults whose mental capacity is restricted due to mental disability. [16] It pointed out that the Civil Code "*distinguishes between full capacity and full incapacity, but it does not provide for any borderline situation.*" [17] The Court stressed that Russian legislation did not provide for a response tailored to the individual needs of a given person. In its ruling, the Court also referred to the principles formulated in a recommendation of the Council of Ministers to the Member States of the EU, concerning the protection of the human rights and dignity of persons with mental disorders.

[14] UN Enable – declarations and reservations, Canada,. http://treaties.un.org.
[15] ECtHR, *Shtukaturov v. Russia,* 2008; See: D.P. BJÖRGVINSSON, "The Protection of the Rights of Persons with Disabilities in the Case Law of the European Court of Human Rights", in O.M. ARNARDÓTTIR and G. QUINN (eds.), *The UN Convention on the Rights of Persons with Disabilities. European and Scandinavian* Perspectives, Leiden, Martinus Nijhoff Publishers, 2009, (141) 152-153.
[16] ECtHR, *Shtukaturov v. Russia,* 2008, §94-96.
[17] ECtHR, *Shtukaturov v. Russia,* 2008, §95.

[18] The general principals included recommendations concerning less intrusive alternatives to legal guardianship,[19] the idea of maximum preservations of a person's legal capacity,[20] the necessity of a proportionality analysis to determine whether measures are necessary and correspond to the needs of the individual[21], the need for respect for the wishes of the individual concerned,[22] and the need to limit the duration of any restrictive measure.[23] With respect to medical interventions the recommendation proclaims the principle of informed consent where possible, even when a person is subject to a measure of protection.[24] Even though the Court did not expressly propose the supported decision-making model, it clearly accepted that the needs of the individual needed to be of guidance. This seemed to be a good first step in the direction of the CRPD.

Unfortunately, the Court seemed much more willing to accept restrictions or even the deprivation of legal capacity in a later decision. In *Lashin v. Russia*,[25] the ECtHR ruled that states can refer to a number of legitimate aims in justifying the deprivation of legal capacity.[26] According to the Court some form of denial or restriction of legal capacity, such as partial guardianship, may be necessary for "*mentally ill persons*". This ruling was the result of a challenge by Mr Lashin, who suffered from schizophrenia, against a court ruling that he lacked capacity. Attempts to restore his legal capacity failed. When Mr. Lashin's health deteriorated, he was admitted to hospital and his father was replaced as his guardian by the hospital where he resided. The hospital, in its capacity of guardian, revoked the request to review his hospitalisation. The Court noted that a decision restricting someone's legal capacity can infringe on the rights listed in article 8 of the Convention. States enjoy a margin of appreciation in deciding whether legal capacity can be restored and to what extent. The extent of the margin of appreciation is influenced by two factors: firstly, when a measure has a drastic effect on a person's autonomy, the Court will apply a stricter scrutiny. Secondly, the Court will pay special attention to the quality of the domestic legal safeguards. The process must be fair and such as to ensure due respect of the interests safeguarded by article 8.[27] The vulnerability of the targeted group can again strengthen the protection.

In a 2012 decision, the Court took yet another view and stressed the importance of support in decision-making by a legally incapable minor.[28] It will be interesting to see if the controversy at the

[18] Recommendation R(99)4 adopted by the Committee of Ministers of the Council of Europe on 23 February 1999 concerning the protection of the human rights and dignity of persons with mental disorder.
[19] Principle 2 – Flexibility in legal response.
[20] Principle 3 – Maximum preservation of capacity.
[21] Principle 5 – Necessity and subsidiarity and Principle 6 –Proportionality.
[22] Principle 9 – Respect for wishes and feelings of the person concerned.
[23] Principle 14 – Duration, review and appeal.
[24] Principle 22 – Consent.
[25] ECtHR, *Lashin v. Russia*, 2013.
[26] ECtHR, *Lashin v. Russia*, 2013, §80.
[27] ECtHR, *Lashin v. Russia*, 2013, §81.
[28] ECtHR, *N.B. v. Slovakia*, 2012. Because the case concerned a sterilisation procedure, it will be further discussed below.

UN level will continue to blur the path of the ECtHR in relation to legal capacity. If the Court continues on the path of supported decision-making, the path it chose in relation to consent of minors, it would clearly indicate executing the CRPD provision and adopting the principle of autonomy. The support offered to accommodate a free and informed consent, even if the level is high, will not violate this principle.

3. Sterilisation

A. Definitions

Sterilisation is defined as the medical process or act that renders an individual incapable of sexual reproduction.[29] It is a method of contraception that is not readily or reliably reversible.

Voluntary sterilisation on the one hand represents the free and uncoerced choice of an individual to limit his or her ability to have children in the future.[30] Non-consensual sterilisation on the other hand occurs when the sterilisation is not the result of a free and informed choice of the individual concerned. Two manifestations of non-consensual sterilisation can be identified. Firstly, forced sterilisation occurs when a person is sterilised after expressly refusing the procedure, when the procedure is conducted without the individual's knowledge or when there was no opportunity to provide consent. The second type of non-consensual sterilisation is the coerced sterilisation which takes place when misinformation or intimidation tactics are used to compel an individual to undergo the procedure. Both forms of sterilisation are captured by the terms involuntary, compulsory or non-consensual sterilisation. These are the all-embracing terms that will be used below.

It was explained above that complete legal incapacity is no longer accepted under the CRPD. Individuals encountering difficulties in reaching the point of the free and informed consent due to mental, intellectual or psychosocial disability, will need to be provided with a suitable level of support in order to exercise their free will. It will become clear that the legal incapacitation of individuals with these disabilities will be of little importance in distinguishing between voluntary and compulsory sterilisation. We will start by discussing the vulnerability of individuals with (intellectual) disabilities. This will help to explain the level of scrutiny the ECtHR uses in sterilisation cases. We will subsequently explore the compulsory sterilisation of individuals with disabilities. The protection offered by the CRPD will be contrasted and compared with the protection following from the case-law of the ECtHR. We will then discuss whether individuals with intellectual disabilities enjoy any

[29] Mosby's Medical dictionary, 8th Edition, 2009, Elsevier.
[30] D.S. DIEKEMA, "Involuntary Sterilization of Persons with Mental Retardation: An Ethical Analysis", 2003, 9 *Mental Retardation and Developmental Disabilities Research Reviews* 21-26.

additional protection against compulsory sterilisation due to their vulnerability. In the last part, we will look into the voluntary sterilisation of individuals with intellectual disabilities.

B. Vulnerability

In the CRPD as well as in the case-law of the ECtHR, special attention is paid to the vulnerable status of individuals with disabilities due to their historical discrimination.

It is apparent from the need for a provision on sterilisation of individuals with disabilities that the drafters of the CRPD considered this group particularly vulnerable. According to the CRPD, groups that have in the past been at great risk of violence and abuse, and thus also of (forced) sterilisation, are women and children with disabilities.[31] Within the group of individuals with disabilities, it seems that intellectually disabled individuals are at particular risk of being sterilised because they cannot always appreciate the consequences of this type of procedure to the fullest and sometimes they are not able to express their will.[32] These concerns have led to a number of provisions serving to enhance the protection. We will discuss them in detail below.

Though it took the ECtHR some time to expressly acknowledge it, the Court has also noticed the delicate position of individuals with disabilities, notably individuals with intellectual disabilities.[33] The characterisation by the Court of a group as vulnerable is important because it leads to an increase of the protection against intrusions of fundamental rights.[34] When a group is considered vulnerable, the Court limits the margin of appreciation a state enjoys in taking measures that affect these groups.[35] In *Alajos Kiss v. Hungary*,[36] a case concerning the right to vote of a person placed under partial guardianship, the Court initially awarded the State a large margin of appreciation in determining whether restrictions on the right to vote can be justified and, if so, how a fair balance is to be struck. Despite this wide margin of appreciation the Court did not accept an absolute bar on voting by any

[31] The Preamble of the CRPD (q) recognises that women and girls with disabilities are at greater risk of violence, injury, abuse, neglect or negligent treatment, maltreatment or exploitation; See also: C. FROHMADER and S. ORTOLEVA, "The Sexual and Reproductive Rights of Women and Girls with Disabilities", written for: ICPD Beyond 2014 International Conference on Human Rights held at the Hague, Netherlands from 7 – 10 July 2013, available on: http://wwda.org.au.

[32] On several occasions, India stressed the vulnerability of individuals with intellectual disabilities. : Ad Hoc Committee, Report of the third session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 9 June 2004, www.un.org.

[33] The vulnerability was not yet mentioned in ECtHR, *X and Y v. The Netherlands*, 1985. This was a missed opportunity as this finding could have been a ground for increasing the protection of individuals with disabilities. In this case the finding of the violation was based on the gap in the law which prevented bot the intellectually disabled young woman and her parents from instituting proceedings. See: A. DIMOPOULOS, *Issues in Human Rights Protection of Intellectually Disabled Persons*, Surrey, Ashgate, 2010, 90-91.

[34] L. PERONI and A. TIMMER, "Vulnerable Groups: The Promise of an Emerging Concept in European Human Rights Convention law", 2013, 11 *International Journal of Constitutional Law* 1056-1085.

[35] This was inspired by the American tiers of scrutiny, see: S. SOTTIAUX and G. VAN DER SCHYFF, "Methods of international human rights adjudication; Towards a more structured decision-making process for the European Court of Human Rights", 2008, 31 *Hastings International and Comparative Law Review* 115-156.

[36] ECtHR, *Alajos Kiss v. Hungary*, 2010.

person under partial guardianship, irrespective of his or her actual faculties. The Court decreased the margin of appreciation again because of the vulnerability of individuals with intellectual disabilities. According to the Court "*such groups were historically subject to prejudice with lasting consequences, resulting in their social exclusion. Such prejudice may entail legislative stereotyping which prohibits the individualised evaluation of their capacities and needs*"[37] With this approach the Court not only accepted the need to increase the protection granted to persons with (intellectual) disabilities, the Court also clearly took the first steps towards embracing the social model of disability. Recent case-law confirmed the acceptance by the Court of the vulnerability of individuals with disabilities.[38] This underlying idea will help clarify some of the Court's decisions.

C. Non-Consensual sterilisation

a) Introduction

Non-consensual sterilisation is best illustrated by the US Supreme Court decision of *Buck v. Bell* mentioned before.[39] In 1927 the US Supreme Court was confronted with a constitutional challenge to Virginia's laws concerning forced sterilisation regulation. Carrie Buck, a young woman who had been committed to an institution for epileptics and feeble-minded was under an order to undergo non-consensual sterilisation. She was the daughter of a mentally retarded woman who had been a resident at the same institution and prior to her admission she had given birth to a daughter who was considered of 'defective mentality'. Later it was reported that the mother was only mildly mentally disabled while the infant who was only a month old when she was labelled as mentally defective, was in fact not mentally retarded at all.[40] The question before the US Supreme Court was whether Virginia's sterilisation laws were in breach of the due process clause of the fourteenth amendment. It was argued that the involuntary sterilisation of Carrie Buck would violate her constitutional right to bodily integrity or more specifically the inherent right of mankind to go through life without mutilation of reproductive organs.[41] The argument on behalf of the defendant included reference to legal competence. Counsel noted that individuals who were not considered incompetent could obtain sterilisation through the exercise of free and informed choice. Therefore he contended that equality required the provision of this procedure for those who are considered

[37] ECtHR, *Alajos Kiss v. Hungary*, 2010, §42.
[38] ECtHR, *Kiyutin v. Russia*, 2011, § 48.
[39] US Supreme Court, *Buck v. Bell*, 1927, 274 US 200.
[40] The girl died of measles in 1932 but she had by that time completed the second grade of school and she had proven to be a very bright child. R.L. BURGDORF JR. and M.P. BURGDORF, "The Wicked Witch is Almost Dead: Buck v. Bell and the Sterilization of Handicapped Persons", 1977, 50 *Temple Law Quarterly* (995) 1006-1007.
[41] US Supreme Court, *Buck v. Bell*, 1927, 274 US (200) 202.

legally incapable.[42] The US Supreme Court upheld the statute and thus gave legal sanction to the sterilisation of a great number of individuals. The decision was severely criticised on the grounds of inaccuracy of its facts and the questionable philosophical underpinnings.[43] Justice Holmes, writing for the majority opined that "*it is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind." He coldly added: "Three generations of imbeciles are enough*".[44] In this decision the Court articulated the eugenic view that later also inspired the Nazi regime to implement a large-scale sterilisation and euthanasia program. Many European countries adopted eugenic laws in the 20th century providing for sterilisation through judicial procedure.[45]

The eugenics movement arose as a result of a primitive understanding of the hereditability of physical traits. The programs stemmed from the worry that the desirable and sensible parts of the population would practice birth control and gradually die out, while the sexually careless and reckless would have lots of children and come to dominate the population. Selective birth control schemes could remedy this imbalance. Sterilisation was even considered necessary and legitimate out of the concern for keeping the human race pure and without defects. Often these laws provided for sterilisation of men as well as women because of behaviour, disability or ethnic origin. Sterilisation was found necessary to protect the wellbeing of the State community or family, in particular because the potentially disabled offspring would place a burden on resources and services since parents with disabilities, mostly mothers, are not regarded as fit for caring for their children.[46] Other reasons besides eugenics to justify the non-consensual sterilisation of individuals with disabilities include prevention of expressions of sexuality, decreased chances of sexual exploitation, reduced likelihood of acquiring sexually transmitted diseases. Sometimes the permanent sterilisation is considered easier than teaching menstrual hygiene.[47] In another incarnation of sterilisation, some countries with high rates of HIV infection used forced sterilisation to prevent mother-to-child HIV transmission during childbirth.[48] This procedure has remained common in some countries despite the fact that the risk of transmission has been greatly reduced by the development of medication in the 1990s. These

[42] US Supreme Court, *Buck v. Bell*, 1927, 274 US (200) 203-204.
[43] For example: E.Z. FERSTER, "Eliminating the Unfit – Is Sterilization the Answer?" 1966, 27 *Ohio State Law Journal* (591)617; J.B. GEST, "Eugenic Sterilization: Justice Holmes v. Natural Law", 1950, 23 *Temple Law Quarterly* 306; J.B. O'HARA and T.H. SANES, "Eugenic Sterilization", 1956, 45 *Georgetown Law Journal* (20) 29-32L
[44] US Supreme Court, *Buck v. Bell*, 1927, 274 US (200) 207.
[45] R.L. BURGDORF JR. and M.P. BURGDORF, "The Wicked Witch is Almost Dead: Buck v. Bell and the Sterilization of Handicapped Persons", 1977, 50 *Temple Law Quarterly* (995) 995-998.
[46] ECtHR, *Gauer v. France*, 2012, written comments: Center for reproductive rights, European Disability Forum, International Center for the Legal Protection of Human Rights (Interights), International Disability Alliance and Mental Disability Advocacy Center, 2011, 6;
[47] For example in Marion's case: High Court of Australia, *Secretary of the Department of Health and Community Services v JWB and SMB*, (1992) 175 CLR 218.
[48] P. NAIR, "Litigating against Forced Sterilization of HIV-Positive Women: Recent Developments in Chile and Namibia", 2010, *23 Harvard Human Rights Journal*, (223) 224.

medications are inexpensively available even in countries without fully developed health care systems.

The ethical implications of involuntary sterilisation are grave.[49] The physical and psychological impact of the procedure is reported to be profound. The shady past of non-consensual sterilisation of individuals with disabilities in the large eugenics programs also leaves its mark. Forcibly or coercively ending a person's reproductive capacities can in some countries lead to exclusion from the community and subsequently (extreme) isolation. In the case of intellectually disabled individuals forced sterilisation is not just a matter of interfering with a person's right to bodily integrity, but it may also lead to situations where a person is sterilised without his express knowledge or against his will. Usually this is the result of the restriction of their legal capacity.

In 1942 the US Supreme Court in *Skinner v. Oklahoma*[50] acknowledged that the right to procreate is of a fundamental nature, requiring a compelling state interest to justify interference. The eugenicists' ideals could no longer justify an intrusion on an individual's fundamental right to make reproductive decisions without the interference of others and without the unconsented bodily invasion inherent to the sterilisation procedure.[51] Additionally, the development of new contraceptives has had an influence on the debate. Effective and long-term contraception is a present-day alternative to the irreversible sterilisation.

Even though most sterilisation laws in the USA and in Western Europe have been repealed, this has not yet resulted in complete renunciation or cessation of non-consensual sterilisation. This is illustrated by a number of cases before the European Court of Human Rights concerning the non-consensual sterilisation of women, mostly of Roma origin but also women with intellectual disabilities. In framing the UN Convention on the Rights of Persons with Disabilities, it was found necessary to include a provision on sterilisation in an attempt to improve and strengthen the right to physical integrity.[52]

b) Protection against non-consensual sterilisation

Under the European Convention on Human Rights the protection against non-consensual sterilisation is derived from article 8 which guarantees the right to respect for private and family life. The article is formulated vaguely without direct reference to the protection against compulsory sterilisation. However, the case-law of the ECtHR has gradually expanded the meaning of private and family life to include the protection of bodily integrity. Article 8 also encompasses the right to personal autonomy,

[49] D.S. DIEKEMA, "Involuntary Sterilization of Persons with Mental Retardation: An Ethical Analysis", 2003, 9 *Mental Retardation and Developmental Disabilities Research Reviews* 21-26.
[50] US Supreme Court, *Skinner v. State of Oklahoma, 1942,* 316 US 535.
[51] D. PFEIFFER,"Eugenics and Disability Discrimination", 1994, 9 *Disability & Society* 481-499.
[52] The discussions concerning the wording of this provision were fierce: Ad Hoc Committee, Daily summary of discussions at the fourth session related to Article 14, Respect for Privacy, the Home and the Family, 27 August 2004, www.un.org.

personal development and the right to establish and develop relationships with other human beings, including the right to respect for a person's decision to become or not to become a parent.[53] Public authorities must refrain from interfering with these rights unless the interference can be justified on the grounds listed in article 8, paragraph 2. Examples of these interferences include forced contraception, abortion, sterilisation and dissuasive measures such as taxes on new births.[54] The interference with the right has to be in accordance with the law and necessary in a democratic society (for reasons of health or morals). The necessity can only be accepted if compelling reasons are relied upon. Unfortunately article 8 does not offer more guidance than this as it is a general human rights instrument which was adopted long before disability became an issue under human rights law. It was not specifically drafted to protect the rights of individuals with disabilities nor was it specifically aimed at preventing intrusions such as non-consensual sterilisations.[55]

The Court has had the opportunity to fine-tune the guarantees derived from the article in cases relating to the non-consensual sterilisation of a number of Roma-women.[56] These women alleged being forcibly sterilised during delivery by caesarean section. The women all stated they had been sterilised without prior information concerning the implications of the surgery. Consent was obtained while they were in labour and in pain or after administering anaesthesia. In some of the presented cases the consent form contained only a small provision on sterilisation which was illegible or in Latin. Some of the applicants stated that their Roma ethnicity was a deciding factor in their sterilisations. The Court decided that *"the sterilisation procedure grossly interfered with the applicant's physical integrity as she was thereby deprived of her reproductive function. At the time of her sterilisation the applicant was twenty years old and therefore at an early stage in her reproductive life.*[57]*"* According to the Court sterilisation lacks the urgency to be considered a life-saving procedure. It can thus not be performed without the prior and informed consent of the patient even when medical staff believes a future pregnancy would put the patient's life at risk. The Court further noted that only exceptional circumstances in which medical treatment cannot be delayed and where the appropriate consent cannot be obtained, can justify a sterilisation without prior consent.[58] The Court added that the patients were not treated with respect for human dignity and human freedom by not giving them enough time and information to make a free and informed decision. The minimum level of severity required to bring it under the scope of article 3 ECHR concerning inhuman and degrading treatment, was reached.[59] This decision shows the importance of the key concept of the free and informed consent. Without free and informed consent, the

[53] ECtHR, *Evans v. The United Kingdom*, 2007, §71.
[54] ECtHR, *Dickson v. the United Kingdom*, 2007.
[55] A. DIMOPOULOS, *Issues in Human Rights Protection of Intellectually Disabled Persons*, Surrey, Ashgate, 2010, 78.
[56] ECtHR, *V.C. v. Slovakia*, 2011; ECtHR, *I.G. and others v. Slovakia*, 2012; ECtHR, *N.B. v. Slovakia*, 2012.
[57] ECtHR, *V.C. v. Slovakia*, 2011.
[58] ECtHR, *V.C. v. Slovakia*, 2011, §108.
[59] ECtHR, *V.C. v. Slovakia*, 2011, §119; ECtHR, *I.G. and others v. Slovakia*, 2012, §122-125.

sterilisation cannot be performed. This precondition raises difficulties when a legal system facilitates the legal incapacitation of individuals with intellectual disabilities because they would no longer be capable of freely consenting.

The Court accepts that article 8 ECHR contains prohibitions as well as positive obligations.[60] In the case of sterilisation these positive measures relate to introducing legislation which imposes the provision of relevant information on the one hand and to securing the reproductive rights of individuals through stringent and effective legal safeguards on the other hand. Information needs to be made available on the topic of reproduction in general, on the different methods of contraception and on sterilisation and its implications. In the case of *I.G. and others v. Slovakia*, another case on forced sterilisation of Roma women, the Court noted that the Slovakian authorities had failed to comply with these positive obligations.[61]

Case-law shows that the ECtHR sometimes looks beyond its own jurisprudence in order to give a comprehensive and contemporary interpretation of the ECHR. The CRPD has already served as a source of inspiration to the Court in cases concerning individuals with disabilities in the past.[62] The principles of the CRPD, which are detailed and contain a lot of positive obligations, are discussed below. It is to be expected that these principles will guide the Court when it is presented with a case concerning the forced sterilisation of individuals with disabilities.

Article 23 is a crucial provision of the CRPD on non-consensual sterilisation. It guarantees the right to respect for home and the family. Paragraph 1 requires that states "*shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships on an equal basis with others."* Sentence (c) states that "*persons with disabilities, including children, retain their fertility on an equal basis with others.*" During the negotiations of the Convention some countries suggested that non-consensual sterilisation needed to be explicitly forbidden. Other states opposed this explicit wording. The compromise that was reached was a more positive wording that persons with disabilities have the right to "*retain their fertility on an equal basis with others*." The provision should make it increasingly difficult for national jurisdictions to authorise non-consensual sterilisations when these are not imposed by medical necessity. The CRPD Committee, like other monitoring bodies of the other UN human rights treaties[63], has found that forced sterilisation breaches multiple provisions of the

[60] For example: ECtHR, *Dickson v. the United Kingdom*, 2007, §69-71.
[61] ECtHR*, I.G. and others v. Slovakia*, 2012, §137.
[62] For example: ECtHR, *Alajos Kiss v. Hongarije*, 2007; ECtHR*, Z.H. v. Hongarije*, 2012, § 43-44.
[63] For example CEDAW Committee, General Recommendation 19, 1992, contained in UN Doc. A/47/38: *"Compulsory sterilization…adversely affects women's physical and mental health, and infringes the right of women to decide on the number and spacing of their children.";* CEDAW Committee, *A.S. v. Hungary, 2004*, UN Doc. CEDAW/C/36/D/4/2004;

respective treaties such as the right to bodily integrity, family and fertility, the right to health and legal capacity.[64]

Article 23 clearly contains the obligation to refrain from interfering with the listed rights, but it also expressly includes positive obligations including the obligation to provide information and legal safeguards. Article 23, 1. (b) states that States Parties are under the obligation to ensure access to age-appropriate information and to recognise reproductive and family planning education. Parties also agreed to actively provide the means necessary to exercise these rights. Additionally states are held to put in place effective legislation and policies to ensure that instances of exploitation, violence and abuse against women with disabilities are identified, investigated and prosecuted.

The CRPD Committee pointed out that States Parties should report on measures taken to protect girls and women with disabilities from forced abortions.[65] The positive obligations, namely providing support in order to ensure that the women themselves are the ones who give their informed consent for legal abortion were also underlined.[66] In relation to sterilisation the Committee expressed concern about the lack of clarity in the scope of legislation to "*protect persons with disabilities from being subjected to treatment without their free and informed consent*."[67]

In addition to the positive obligations under article 23, Article 25 contains the right to enjoyment of the highest attainable standard of health. It requires states to ensure that health professionals give substance to the human rights of all individuals, including those with (mental) disabilities by providing high quality health care without discrimination on the basis of free and informed consent and according to the principles of accessibility and acceptability. Services must include the provision of sexual and reproductive health and population-based health programmes.

It is clear that both the CRPD and the ECtHR require a strong protection against non-consensual sterilisation of individuals with disabilities.

c) Non-consensual sterilisation of individuals with intellectual disabilities

Persons with intellectual, mental and psychosocial disabilities are at greater risk of involuntary sterilisation. This was illustrated by the concluding observations of the CRPD Committee on the state

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CEDAW Committee, *L.C. v. Peru*, 2009, CEDAW/C/50/D/22/2009, CRC Committee, General Recommendation 13, 2011, CRC/C/GC/13, all available on: www.ohchr.org.

[64] The CRPD Committee found forced sterilisation to be in breach of article 17 in: CRPD Committee, Concluding Observations on the Initial Report of Argentina, 2012, UN Doc. CRPD/C/ARG/CO/1, §3132 and in breach of article 23 in: CRPD Committee, Concluding observations on the Initial Report of Hungary, UN Doc. CRPD/C/HUN/CO/1; in breach of article 6: CRPD Committee, Concluding Observations on the Initial Report of Paraguay, 2013, UN Doc. CRPD/C/PRY/CO/1, §17, available on: www.ohchr.org.

[65] CRPD Committee, Guidelines on treaty-specific document to be submitted by States Parties, 2009, UN Doc. CRPD/C/2/3, §11-13.

[66] CRPD Committee, Concluding Observations on the Initial Report of Argentina, 2012, UN Doc. CRPD/C/ARG/CO/1, §32.

[67] CRPD Committee, Concluding Observations on the Initial Report of Tunisia, 2011, UN DOc. CRPD.C/TUN/CO/1CRPD, §28.

reports of China and Peru.[68] The Committee expressed serious concerns in relation to the well spread practice of forcibly sterilising mentally incompetent individuals. This greater risk results in a higher need for protection. This even stronger protection will be discussed in this section.

In the case of intellectually disabled individuals, the concept of the free and informed consent which serves to determine whether a sterilisation is conducted voluntarily or against a person's will, is problematic. The assumption is easily made that persons with intellectual disabilities are incompetent to receive and process information, especially when it concerns important life choices.

Requests for sterilisation are often introduced by legal guardians. Usually the motives of these guardians are rooted in (legitimate) concerns for the person with a disability. Sometimes the best interest of the person with a disability does not (completely) coincide with the concerns of thirds, including guardians.[69] In some cases the sterilisation is requested without the existence of an actual need for intrusive measures whereas in other cases the motives are not of a nature that can justify a procedure of that kind, for example the wish to limit financial expenditures. The decision to sterilise is thereupon usually made by medical professionals[70] under the assumption that the person with a disability is unable to understand the procedure and its implications.[71]

The importance of just motives was demonstrated in a 1986 Canadian case[72]. The motives to request a sterilisation consisted of a mother's fear of her disabled daughter falling pregnant and of the mother's subsequent responsibility for rearing het grandchild. The Court held that benefit to others or to society is not a ground for executing non-therapeutic surgery that could potentially violate the physical and mental integrity. The intervention would be excessive for the stated purpose.[73]

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[68] CRPD Committee, Concluding observations on the initial state report of Peru, UN Doc. CRPD/C/PER/CO/1; CRPD Committee, Concluding observations on the initial state report of China, UN Doc. CRPD/C/CHN/CO/1.

[69] The criterion of the best interest of the person concerned has been criticised after the introduction of the CRPD for its paternalistic character. It still allows for decisions to be made about an individual without his participation. The CRPD does no longer rely on it except for decisions concerning children. See: Article 7, §2 CRPD; L.M. KOPELMAN, "The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages", 2007, 35 *Journal of Law, Medicine & Ethics* 187-196; J.C.M. WILLEMS, "Principles and Promises in the CRC and the CRPD", in L. WADDINGTON, G. QUINN and E. FLYNN (eds.), *European Yearbook of Disability Law - Volume 3*, Antwerp, Intersentia, 2012, (59) 70-71.

[70] When a sterilisation is conducted out of concern for the well-being of the persons with a disability, the sterilisation is considered therapeutic and in the best interest of the individual concerned. In the Australian case named *Marion's* case, an application was made for non-therapeutic surgical sterilisation to manage menstruation and prevent pregnancy of an intellectually disabled teenager. The Australian High Court found that fundamental rights, such as the right to reproduce should be decided by the courts rather than by parents or medical practitioners. High Court of Australia, *Secretary of the Department of Health and Community Services v JWB and SMB*, (1992) 175 CLR 218.

[71] C. FROHMADER and S. ORTOLEVA, "The Sexual and Reproductive Rights of Women and Girls with Disabilities", written for: ICPD Beyond 2014 International Conference on Human Rights held at the Hague, Netherlands from 7 – 10 July 2013, available on: http://wwda.org.au.

[72] Supreme Court of Canada, *E. v. Eve*, [1986] 2 S.C.R. 388.

[73] Even though the Supreme Court in fact endorsed the human rights approach and refused to allow sterilisation of a young woman with intellectual disabilities, the court accepted her characterisation as incompetent. The Court's opinion was that she was incapable of making decisions regarding her personal relationships and reproductive health.

So far only one case concerning the non-consensual sterilisation of individuals with an intellectual disability has been presented before the ECtHR.[74] This case involved five young women with intellectual disabilities who had been forcibly sterilised in France between 1995 and 1998. They had not been informed about the implications of the surgical procedure and their consent was unnecessary. The parents had not consented nor had they shown any intention to do so. Because the legal capacity of the young women had been restricted, they had not been able to initiate legal proceedings. The non-governmental organisation representing these women lodged a criminal complaint in France which was dismissed because the Court found that the surgical procedure was performed for medical reasons, was not irreversible and had not been illegal. The Court also found that the applicants had not been permanently disfigured. Before the ECtHR counsel alleged a breach of Article 3 (freedom from torture, inhuman, degrading treatment or punishment), Article 6 (right to a fair trial including access to courts), Article 8 (private and family life), and Article 14 (non-discrimination). The decision of the ECtHR was expected to be an important statement on the reproductive rights of persons with disabilities and the positive obligations on the States in safeguarding persons with disabilities against compulsory health treatment and abuse but the application was considered inadmissible on procedural grounds and was thus never decided on the merits. Therefore the Court has not yet directly answered the fundamental question of the strength of the protection offered to individuals with intellectual disabilities against involuntary sterilisation under the ECHR and the second core issue of the restriction of legal capacity for individuals with an intellectual disability. However, the Court has in another case acknowledged that the consent of a legal guardian does not necessarily mean that treatment was voluntarily undergone.[75] In this case on forced hospitalisation, the Court stressed the importance of hearing the patient. Above we established that the finding that a person is intellectually disabled will lead to an increased scrutiny on the basis of the vulnerability.

The silence of the ECtHR on this matter stands in contrast to the clarity of the CRPD. In the first place, the states are under the obligation to modify the system of legal incapacitation to ensure that all individuals can express their will. A correct interpretation of article 12 would immediately strengthen the protection offered to individuals with intellectual disabilities. Additionally, article 23 mentioned above also applies to individuals with intellectual disabilities. The nature of the disability cannot be a reason to violate the protection. The CRPD contains even more principles which would be violated by the non-consensual sterilisation of individuals with intellectual disabilities. The main principles of the CRPD include autonomy and respect for human dignity.[76] Autonomy implies that others need to respect the right of a person to hold views, make choices and take actions without interference. The

[74] ECtHR, *Gauer v. France*, 2012.
[75] ECtHR, *Lashin v. Russia*, 2013.
[76] Preamble (n).

principle entails a negative obligation (the duty to refrain from interferences) but may also include positive obligations (the obligation to enable and enhance the ability to make choices). According to the principle of autonomy, it is the person concerned who is best able to determine whether sterilisation is the right decision for him. The individual needs to be provided with an appropriate level of support if this is needed. Involuntary sterilisation represents a clear violation of the respect for autonomy. DIMOPOULOS advances the idea of providing veto rights for individuals with intellectual disabilities as a way to advance the goal of ensuring human dignity and autonomy.[77] Persons with disabilities may not be deemed competent to consent to treatment, yet this does not mean that they are also incapable of objecting. This is a very strong means to reach the stated goals, however, veto-rights would be unnecessary if supported decision-making would replace legal incapacity and legal guardianship. Veto-rights are an inherent part of the new scheme. If the paradigm shift is not completed, or if the tailor-made model of substituted decision-making for those who can never reach capability still does not offer sufficient protection, express and additional veto-rights can be a very useful instrument.

Another CRPD provision aimed at protecting individuals with disabilities against involuntary treatment is Article 17, concerning "*the right to respect for his or her physical and mental integrity on an equal basis with others*". This article serves to ban a range of practices commonly found in psychiatric care that compromise the physical and mental integrity of the person. These cases often have in common that the institution or hospital, sometimes appointed as guardian, consents to medical treatment on behalf of the patient. Sometimes this treatment is administered without the knowledge or against the express will of the patient. The UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment identified among others forced abortion or sterilisation without free and informed consent.[78] The provision of the CRPD clearly states that admission to hospital cannot result in a free pass for amongst others sterilisation.

D. Consensual sterilisation – individuals with intellectual disabilities

a) Introduction

Sterilisation of persons with disabilities poses two distinct problems. The first one, the non-consensual sterilisation (in general and in the specific case of individuals with intellectual disabilities) was discussed above. The other issue affects individuals who are legally incapacitated and are therefore not free to decide on permanent sterilisation by themselves. This second problem was illustrated in the British

[77] A. DIMOPOULOS, *Issues in Human Rights Protection of Intellectually Disabled Persons*, Surrey, Ashgate, 2010, 178.
[78] Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, J.E. Méndez, 1 February 2012, UN Doc. A/HRC/22/53, §46-48.

decision of the Court of Protection discussed in the introduction. DE requested the sterilisation himself but had to go through court proceedings before a medical professional was willing to perform the surgery. The presumption in most legal systems is that competent adults are at liberty to consent to or refuse proposed medical treatment. Individuals with intellectual, mental or psychosocial disabilities on the other hand, are often considered to lack decision-making skills and are therefore considered incapable to give the free and informed consent which is needed for intrusive operations such as abortion or sterilisation.[79] This results in the impossibility for the person to make a legally valid decision. There seem to be two reasons for prudence in relation to sterilisation requests made by individuals with disabilities. The first reason is that individuals who are legally incapable, are generally perceived to lack the necessary understanding of the ramifications of the procedure and should for that reason be protected from ill-considered decisions. Secondly, the generally irreversible nature of the procedure requires cautiousness.[80] Despite these good reasons, the restriction on the legal capacity of these individuals strongly interferes with their autonomy, identified as one of the main principles of the CRPD.[81] Respect for autonomy results in allowing the individual to weigh the important information and reach his own decision concerning sterilisation, if necessary with support.

b) Voluntary sterilisation

The CRPD states in article 23 that individuals have the right to enjoy their fertility on an equal basis with others. This includes keeping one's reproductive capacities. The other side of the coin allows individuals to freely choose to have their reproductive capacities limited. This right poses problems when it is claimed by persons with intellectual disabilities if their legal capacity is restricted or deprived. A fair balance needs to be struck between on the one hand protecting the individual with a disability from making irreversible life choices with a profound impact and on the other hand granting him the autonomy the Convention aims at in order to fulfil other values such as human dignity.[82] Complete legal incapacity is generally no longer possible. A person with an intellectual disability will need to balance the information he finds and receives, and reach a decision, if necessary with an appropriate level of support. The CRPD Committee stressed the importance of support in order to ensure that the persons with disabilities themselves are the ones who give their free and informed consent for health decisions including sterilisation.[83]

[79] The importance of the free and informed consent was mentioned above. Both the ECtHR (*V.C. v. Slovakia*, 2011) and article 23 and 25 CRPD.
[80] These were also the High Court of Australia's motives in Marion's case to decide that fundamental questions of human rights should be decided by courts instead of by parents or medical practitioners: High Court of Australia, *Secretary of the Department of Health and Community Services v JWB and SMB*, (1992) 175 CLR 218.
[81] Article 1 CRPD.
[82] This evolution can also be found in the US where Court decided that the right to privacy also entailed the right to choose birth control, including sterilisation. US Supreme Court, *Griswold v. Connecticut*, 1965, 381 U.S. 479.
[83] CRPD Committee, Concluding Observations on the Initial Report of Argentina, 2012, UN Doc. CRPD/C/ARG/CO/1, §32; CRPD Committee, Concluding observations on the Initial Report of Hungary, UN Doc. CRPD/C/HUN/CO/1.

The ECtHR has so far never had the opportunity to deal with the issue of free and informed consent in relation to sterilisation by individuals with disabilities. In one of its rulings on the sterilisation of Roma women, the Court stated that the procedure can only be executed after having obtained the free and informed consent of the patient.[84] The informed consent requires that a patient is given material information, including information about the proposed treatment and its risks, benefits and alternatives. The States are under a positive obligation to provide this information.

In a case concerning the non-consensual sterilisation of a minor, who at the time also lacked legal capacity due to her age, the Court held that the individual had the right to freely decide on the procedure, with the help of a representative.[85] The young woman had been sterilised shortly before her 18th birthday. Neither her opinion nor the mother's consent had been asked. It seems only logical that the Court would adopt this same position when the person requesting the sterilisation was a person with an (intellectual) disability. Good and appropriate support, as it follows from the CRPD, can help remove the barriers for individuals with disabilities in their right not to retain their fertility.

4. Conclusion

Sterilisation of individuals with disabilities is not always a matter of involuntary sterilisation. We established that the dark past of eugenics hinders individuals with disabilities, in particular individuals with intellectual disabilities, in their right to freely decide on their reproductive capacities. What distinguishes one from the other is the concept of free and informed consent. It is obvious that involuntary sterilisation lacks this component. The protection against these practices is strongly embedded in the CRPD as well as in the case-law of the ECtHR. However, this protection can turn into overprotection when individuals with intellectual disabilities are involved. Individuals with these types of disabilities are regularly deemed incapable of freely consenting to intrusive treatment such as sterilisation. For this reason they were often de facto excluded from such surgery. The CRPD provides a new decision-making model, supported decision-making instead of substituted decision-making, based on the abilities of people instead of their (medical) defects. The model is based on principles including autonomy, participation and inclusion. If it is transposed correctly, it would put disabled persons in a position in which their access to such surgery would no longer be hindered by generalising assumptions. The case-law of the ECtHR was studied to examine the extent to which the principles derived from the CRPD have already penetrated. It seems that supported decision-making has not been fully accepted yet. It remains to be seen which general direction the Court will choose.

[84] ECtHR, *V.C. v. Slovakia*, 2011, §108.
[85] ECtHR, *N.B. v. Slovakia*, 2012, §78.